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Confidentiality of Electronic Health Data: Methods for Protecting Personally Identifiable Information

January 1990 through March 1996
448 Selected Citations

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FOREWORD

In 1995, in response to a request from the Vice-President of the United States of America, the Department of Health and Human Services assumed a leadership role in addressing four major issues surrounding the use of the National Information Infrastructure to advance health care and the public health: (1) telemedicine; (2) health data privacy; (3) health data standards; and (4) consumer access to health information. One specific health data privacy objective is the identification and dissemination of information about current best practices for ensuring the confidentiality of electronic health data. This bibliography of information sources that provide concrete guidance on the policies, procedures, and technologies useful in safeguarding electronic health data is a first step toward that objective. Although the bibliography contains many useful references, the literature search conducted to produce it has confirmed that published information about how to protect electronic health data is fragmented and incomplete. Many institutions are currently addressing the need for comprehensive policies and procedures for safeguarding electronic health, but, to date, few institutional documents have been completed and released.

Materials cited in this bibliography have been one source of input to a study of "best practices" for protecting the confidentiality of electronic health care data that is currently being undertaken by the Computer Sciences and Telecommunications Board of the National Research Council, under the chairmanship of Paul Clayton, Ph.D. Columbia-Presbyterian Medical Center. Funded by the National Library of Medicine and the Warren G. Magnuson Clinical Center, National Institutes of Health, DHHS, the study is also collecting data through a series of site visits to institutions with electronic health information systems. Its final report, scheduled for release by January 1997, will bring us a step closer to the goal of developing practical and coherent guidelines for protecting the confidentiality of electronic health data.

Nan D. Hunter
Deputy General Counsel
U.S. Department of Health and Human Services
Chair, Interdepartmental Health Privacy Working Group

CONFIDENTIALITY OF ELECTRONIC HEALTH DATA

Electronic health data can improve the quality and efficiency of health care, research, and public health surveillance and interventions. To achieve these benefits without unacceptable risk to patient confidentiality, electronic health data must be created, used, transmitted, aggregated, and abstracted in ways and in environments that maintain data security and accuracy; prevent inadvertent or accidental release; prevent or deter access by unauthorized users; and discourage detect, and punish inappropriate use of health data by unauthorized users.

This selective bibliography is primarily intended for those who are responsible for protecting electronic health data and need information on appropriate strategies for doing so. It includes references to publications, organizations, and electronic sources that address methods for preserving the confidentiality and security of electronic health data. The methods covered include technical approaches, institutional policies and procedures, staff and patient education, and legal and regulatory requirements. In addition to substantive discussions of measures for preserving confidentiality and security of health data, the bibliography also has references to some recent standards and guidelines that apply to electronic data in general. Letters, editorials, news items, and general descriptions of health information systems in which security and privacy prevention are mentioned briefly generally have been excluded.

The bibliography has a tight focus on how to protect electronic health data and therefore also excludes references to the large body of literature on related topics such as: the need to protect privacy; the need for federal legislation; the potential privacy and security problems associated with computer-based patient records; the public's perceptions of privacy issues; special ethical and privacy considerations associated with genetic screening, AIDS testing, and occupational health records; the conditions under which medical and psychiatric records must or must not be disclosed to courts; the tension between privacy and the public good in cases involving infectious disease, potential violence, etc.; institutional review boards; and informed consent, except as it relates directly to consent about use of health data.

In general, publication dates for references included in this bibliography range from January 1990 through March 1996, and publications are primarily in English. Journal articles, books and book chapters, conference proceedings and papers, meeting abstracts, laws and legal documents, and technical reports, as well as unpublished documents, have been surveyed and selected for inclusion. Arrangement of the bibliography is by subject and citations within each category are listed alphabetically by author; a citation appears under only one category.

A number of Internet sites created by various organizations that address confidentiality or computer security may be found by using various world wide web searching tools. A selected list of these are included in the Organization section of this bibliography. All Internet addresses were functional on the date that this bibliography became available.

The compilers wish to thank Marlyn Schepartz, National Library of Medicine, for her technical assistance with production of this bibliography.

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EXPLODE CLINICAL TRIALS OR EXPLODE *MEDICAL INFORMATICS

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SAMPLE CITATIONS

Citations in this bibliographic series are formatted according to the rules established for *Index Medicus*®*. Sample journal and monograph citations appear below. For journal articles written in a foreign language, the English translation of the title is placed in brackets; for monographs, the title is given in the original language. In both cases the language of publication is shown by a three letter abbreviation appearing at the end of the citation.

Journal Article:

<i>Authors</i>	<i>Article Title</i>
Barrows RC Jr, Clayton PD.	Privacy, confidentiality, and electronic medical records. J Am Med Inform Assoc 1996 Mar-Apr;3(2):139-48.
<i>Abbreviated Journal Title</i>	<i>Date Volume Issue Pages</i>

Monograph:

<i>Authors/Editors</i>	<i>Title</i>
Barber B, Treacher A, Louwerse CP, editors.	Towards security on medical telematics: legal and technical aspects. Washington: IOS Press; 1996. 252 p.
<i>Place of Publication</i>	<i>Publisher Date Total No. of Pages</i>

*For details of the formats used for references, see the following publication:

Patrias, Karen. *National Library of Medicine recommended formats for bibliographic citation*. Bethesda (MD): The Library; 1991 Apr. Available from: NTIS, Springfield, VA; PB91-182030.

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OVERVIEW

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